

# Virginia Department of Health

## Statewide Coordinated Statement of Need 2004

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Finally, a skilled group of facilitators were instrumental in providing a context where all views could be heard. The SCSN process would not have been successful without them.

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## Executive Summary

A steering committee made up of HIV-infected and affected individuals, providers, researchers, and advocates came together in January 2004 and diligently worked to develop an SCSN process that identified cross-cutting issues, developed strategies to address barriers and create broad goals to be used in the comprehensive planning process. “Changing Times, Changing Lives” marked a step towards the HIV community addressing the changing funding and policy issues affecting HIV care. On June 17 and 18, 2004 one hundred and seven attendees from the five Virginia health regions, seventeen facilitators and five Virginia Department of Health (VDH) Staff came together to provide input into the 2004 Statewide Coordinated Statement of Need (SCSN).

During the 1996 Ryan White reauthorization year, Congress enacted legislation requiring all Title II recipients to partake in an SCSN process. The goal was for the SCSN to “be a mechanism for addressing key HIV/AIDS care issues and enhancing coordination across CARE Act program titles.”<sup>1</sup> The process works to bring together HIV-infected and affected individuals receiving services, providers and public agency representatives to describe how resources are allocated and utilized, and to develop the SCSN. The result from the SCSN process is a foundation for comprehensive plan development.

In December 2003, the Ryan White Subcommittee of Virginia’s HIV Community Planning Committee recommended convening an SCSN Steering Committee that would work together to develop the 2004 SCSN process. VDH brought together seventeen individuals who included HIV infected and affected individuals, providers, researchers and advocates from all five health regions of Virginia. Four VDH representatives also staffed the steering committee. For six months, the committee worked through such issues as maximizing the SCSN outcomes in order to drive a more proactive comprehensive plan, assuring a diverse and representative group of participants is convened to provide input, and identifying strategies to effectively evaluate the SCSN process. Overall, the steering committee faced many challenges in developing the 2004 SCSN ranging from differences of opinions to working within funding limitations. The end result was a two-day consumer driven process that included pre-meeting discussion groups and the day-long event itself.

The pre-meeting discussion groups were facilitated by steering committee members and provided people infected and affected with HIV an opportunity to talk about their care experiences. Participants gave mixed comments related to the quality of care they have received from CARE Act funded providers. For some, quality of services received were perceived as excellent, while others reported encountering increasing barriers, identified needs for more knowledgeable and culturally sensitive providers and more monitoring, training and standardization for case management services.

These themes reflected themselves in the SCSN small workgroups the next day. Barriers and gaps to service were often cross-cutting. The most predominant issues included:

- The need for funding, not only for more services, but to provide assistance for medical co-pays and non-HIV-related medications;
- The need for more knowledgeable and culturally competent providers; and

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<sup>1</sup> US Department of Health and Human Services, Health Resources and Services Administration (obtained on-line May 13, 2004). Ryan White CARE Act: Guiding Principles for CARE Act Programs. Available on-line: [www.hab.hrsa.gov/history/principles.htm](http://www.hab.hrsa.gov/history/principles.htm)

- The need for more monitoring, training, and standardization of case management services.

From this, participants worked together to identify system and client-level strategies that could enhance the current service system and address some of the cross-cutting issues. What they identified was an intricately woven web of barriers and gaps that can inhibit an individual from receiving quality services. Towards the end of the day, the workgroups developed eighteen overarching goals to be used in the development of the comprehensive plan. These findings will serve as the basis for formulating Virginia's comprehensive plan for meeting the needs of persons living with HIV and AIDS.

## INTRODUCTION

Since the first reported AIDS case in 1981, approximately 1.5 million people in the U.S. have been infected with HIV. More than 500,000 have died and the remaining continue to live with HIV.<sup>2</sup> Although new treatments have prolonged the life of HIV-infected individuals, it is estimated that 42%-59% of people living with HIV/AIDS are not in regular HIV care, and around one-third do not know they are even infected.<sup>3</sup> HIV is increasingly affecting the uninsured and underinsured communities. It is estimated that 46% of HIV-infected individuals in care have incomes below \$10,000 a year and 63% are unemployed.<sup>4</sup>

Racial and ethnic minorities represent the majority of new AIDS cases. Although African Americans and Latinos represented 12% and 14% of the U.S. population respectively, they accounted for 50% and 20% of new AIDS diagnoses in 2002.<sup>5</sup> Women, and women of color especially, are also a growing proportion of new AIDS cases with 68% of new AIDS diagnoses due to heterosexual contact and 29% to injection drug use.<sup>6</sup> Young adults and teens also continue to be at risk with at least half of all new infections being individuals under 25 years old. Although HIV infection rates among men who have sex with men (MSM) have declined, MSM account for 55% of new AIDS cases and remain at high risk for infection.<sup>7</sup> <sup>8</sup> Because of the disproportionate rate of infection among the poor and unemployed, there is an increased need to provide financial support to ensure access to quality medical care and the support services to facilitate that care.

The Ryan White CARE Act accounts for 22% (\$1.9 billion) of the federal spending on HIV/AIDS care for the uninsured.<sup>9</sup> Other resources include Medicaid, Medicare, private insurance and other publicly supported sources such as the Veteran's Health Administration and federally qualified community health centers.

The Ryan White CARE Act was enacted in 1990 to provide funding for primary health care and support services to enhance access and retention into care for individuals infected and affected by HIV. It was amended in 1996 and again in 2000. The CARE Act includes the following principles:

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<sup>2</sup> The Henry J. Kaiser Family Foundation (2004). The HIV/AIDS Epidemic in the United States. HIV/AIDS Policy Fact Sheet. Washington, DC.

<sup>3</sup> Fleming, P. et al. (2002). HIV Prevalence in the United States, Abstract #11. Oral Abstract Session 5, 9<sup>th</sup> Conference on Retroviruses and Opportunistic Infections, In The Henry J. Kaiser Family Foundation (2004). The HIV/AIDS Epidemic in the United States. HIV/AIDS Policy Fact Sheet. Washington, DC.

<sup>4</sup> Bozzette, S., et al (1998). The care of HIV-infected adults in the United States, New England Journal of Medicine, 339(26). In Kates, J. (2004). Financing HIV/AIDS Care: A quilt with many holes. HIV/AIDS Policy Issue Brief. The Henry J. Kaiser Family Foundation, Menlo Park, CA.

<sup>5</sup> Centers for Disease Control and Prevention (2004). HIV/AIDS Surveillance Report: Cases of HIV Infection and AIDS in the United States, 2002, Vol. 14. Available: <http://www.cdc.gov/hiv/stats/2002SurveillanceReport.pdf>

<sup>6</sup> Ibid.

<sup>7</sup> Ibid.

<sup>8</sup> CDC, (2001). No Turning Back: Addressing the HIV Crisis Among Men Who Have Sex with Men, In The Henry J. Kaiser Family Foundation (2004). The HIV/AIDS Epidemic in the United States. HIV/AIDS Policy Fact Sheet. Washington, DC.

<sup>9</sup> Kates, J. (2004). Financing HIV/AIDS Care: A quilt with many holes. HIV/AIDS Policy Issue Brief. The Henry J. Kaiser Family Foundation, Menlo Park, CA.



- Widen community involvement to structure and revise care systems to meet emerging needs;
- Ensure access to quality HIV/AIDS care;
- Coordinate CARE services with other health care systems to maximize resources; and
- Evaluate CARE services and make necessary improvements.<sup>10</sup>

The CARE Act supports a variety of services for individuals who lack health insurance or other financial resources and facilitates entry into and/or retention in medical care. Over 500,000 people per year are served under the CARE Act and in Fiscal Year 2002, \$1.91 billion was appropriated for medical and support services.<sup>11</sup> Several programs are provided under the CARE Act:

- Title I provides funds to eligible metropolitan areas with highest numbers of persons affected by HIV.
- Title II provides funds to states for health care and support services.
- Title III provides funds for early intervention services.
- Title IV provides services to women, children, youth and families.
- The AIDS Drug Assistance Program (ADAP) provides medications to low-income individuals with HIV who have limited or no coverage from private insurance or Medicaid.
- The CARE Act also funds other projects including the Special Projects of National Significance (SPNS), HIV/AIDS Education and Training Centers, Dental Reimbursement Program, Program Data and Evaluation and Community-Based Dental Partnership Grants.<sup>12</sup>

During the 1996 CARE Act reauthorization, Congress enacted legislation requiring all Title II recipients to partake in a Statewide Coordinated Statement of Need (SCSN) process. The goal was for the SCSN process to “be a mechanism for addressing key HIV/AIDS care issues and enhancing coordination across CARE Act program titles”<sup>13</sup> by bringing together HIV-infected and affected individuals receiving services, providers and public agency representatives.<sup>14</sup>

The results from the SCSN process are then used as a foundation for the state’s comprehensive plan that details the “delivery of health and support services” to HIV-infected and affected individuals. The Virginia Department of Health’s Division of HIV, STD, and Pharmacy Services (VDH) has administered CARE funds since 1991 through five regional consortia (see health district map in Appendix A). Table I illustrates the Ryan White Titles for each region in 2004.

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<sup>10</sup> US Department of Health and Human Services, Health Resources and Services Administration (obtained on-line May 13, 2004). Ryan White CARE Act: Guiding Principles for CARE Act Programs. Available on-line: [www.hab.hrsa.gov/history/principles.htm](http://www.hab.hrsa.gov/history/principles.htm)

<sup>11</sup> US Department of Health and Human Services, Health Resources and Services Administration (obtained on-line May 13, 2004). Ryan White CARE Act: Programs. Available on-line: [www.hab.hrsa.gov/programs.htm](http://www.hab.hrsa.gov/programs.htm)

<sup>12</sup> Ibid.

<sup>13</sup> Human Resources and Services Administration, HIV/AIDS Bureau (2003). Title II Manual, 2003 version. Available: [www.hab.hrsa.gov/tools/title2/](http://www.hab.hrsa.gov/tools/title2/) page. 35.

<sup>14</sup> Ibid

Table 1: Ryan White CARE Act by Virginia Health Region

Region	Area	Title I	Title II	Title III	Title IV
1	Northwest	X	X	X	
2	Northern	X	X	X	X
3	Southwest		X	X	
4	Central		X	X	X
5	Eastern	X	X		

### ***A Brief Overview of the SCSN in Virginia***

The 1996 reauthorization language assigned the responsibility of coordinating the SCSN to the administrative agency that receives Title II funds. VDH developed the first SCSN conducted on October 22, 1997. Ninety-four participants attended, with consumers representing 26%. Eight attendees who functioned as small group facilitators worked with VDH staff after the meeting to draft the SCSN report. The report was then reviewed by attendees and submitted to HRSA as required. Copies of the SCSN report were given to all Ryan White CARE Act funded entities for planning purposes.

The second SCSN was coordinated by VDH in 2000 and included the guidance of a twenty member advisory committee with 50% representation by consumers. Representatives from all five regional consortia, all Titles, Housing Opportunity for People with AIDS (HOPWA), Department of Medical Assistance Services (DMAS), and the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) were included. The theme for the October 12, 2000 SCSN was “100% Access with 0% Disparity.”

The SCSN Advisory Committee met twice a month to plan the meeting. Five-hundred invitations were distributed to all programs funded under Ryan White, other state and federal programs and organizations providing services to People Living With HIV/AIDS (PLWH/A), other stake holders, planning groups, community-based organizations, consumers, providers, public agencies and the Regional HIV/AIDS Resource and Consultation Centers (Centers of Excellence) that were state-funded and provided clinical training to health care providers. One hundred and fifty-five individuals attended of which 61 (39%) were consumers. The Advisory Committee and facilitators met several times after the meeting to develop the report. The document was distributed to all Titles and used for planning purposes.

### **2004 SCSN PROCESS**

#### *Steering Committee*

In December 2003, the Ryan White Subcommittee of Virginia’s HIV Community Planning Committee recommended convening an SCSN Steering Committee that would work together to develop the SCSN process and remain involved through comprehensive planning. Beginning in January 2004, VDH brought together a steering committee consisting of seventeen individuals from all five health regions of Virginia and representing HIV+ individuals, affected individuals, providers, researchers and advocates. Four VDH representatives also staffed the steering committee. From January – June 2004, the steering committee met four times and corresponded through e-mail and telephone as the details of the SCSN process emerged. The steering committee remained dedicated to developing an SCSN process that would result in more useful data than previous SCSNs and include pre-meeting discussion groups with infected and affected individuals. The steering committee also decided to utilize trained facilitators who

worked outside of the HIV/AIDS arena, and structure the small group discussions so the outcomes provided more than just lists of barriers or other challenges, but instead offered possible solutions from members of the community.

The theme for the 2004 SCSN was “*Changing Times, Changing Lives*”. The theme represented the policy and funding changes occurring in HIV/AIDS services and how those changes influenced peoples’ lives. The goal was to have at least 50% consumer representation at the meeting and to move participants beyond barrier and need identification to a more solution-focused process.

The primary concerns of the steering committee involved facilitation of the SCSN to maximize the outcomes of the process; the ability to bring together a diverse and representative group of participants; and evaluation of the process. The steering committee began by analyzing the strengths and weaknesses of the 2000 SCSN and built upon that process by providing more structure to the small discussion workgroups. To address their primary concerns the following strategies were employed by the steering committee:

- **Structured SCSN Groups to Maximize Outcomes:** To avoid having the meeting as didactic as the previous SCSN, the steering committee elected to provide participants with background and reference materials, including acronyms and definitions, prior to the SCSN meeting in June. The steering committee also elected for professional facilitators to guide a number of small groups (15-20 participants each) through a highly structured outline of needs, barriers, overarching themes and goals/strategies. Special thanks go to Chesterfield Parks and Recreation for providing many of the free facilitators. By using professional facilitators not affiliated with specific HIV/AIDS service providers, the process was able to remain more objective and focused on the task at hand. To assist the facilitators, steering committee members volunteered to provide assistance (e.g. recording, providing background information) during the groups. More time was also dedicated to the work groups by limiting the morning session to a brief epidemiology overview of HIV in Virginia and a debriefing of the pre-meeting discussion groups held the evening before.

To maintain the focus of the SCSN on overarching themes and goals, the steering committee decided to conduct pre-meeting discussion groups with infected and affected individuals attending the SCSN. The pre-meeting discussion groups were facilitated by steering committee members experienced in group facilitation. Groups ranged from 8-12 participants each and lasted 90 minutes. The small group discussions, although following a structured question format, allowed participants to describe their personal experiences, frustrations and successes, providing the opportunity to be heard by one another.

- **Bringing Together a Diverse and Representative Group of Participants:** One of the most debated subjects among steering committee members was the number of participants who could attend SCSN. Funding constraints limited the number of attendees (including facilitators and staff) to 125. Many members felt limiting the number of participants could keep out-of-care and newly-infected/affected individuals from attending. The main question became: how could the steering committee recruit a diverse group of individuals, including newly-infected and affected people who haven’t previously attended SCSN?

The steering committee worked within the 125 participant limit and decided that each health region would have 25 representatives. Of the 25, the steering committee requested that at least 15 be HIV-infected and 10 providers. Each potential participant was requested to fill out an application that included their name and basic demographics. The applications were then used to select 25 demographically diverse participants per region that included individuals new to the SCSN process as well as those who had previous SCSN participation. If at the end of registration, a region still had openings, then those openings would be filled by applicants from other regions. Flyers and letters were sent to all Ryan White and prevention providers as well as a letter explaining the importance of recruiting individuals not in care (see Appendix B: Flyer and Application). For individuals who could not attend, a process to offer written feedback was implemented. However, no individuals chose to use this option. Table 2: Application Results by Region, illustrates the number of applications, those that could not be accommodated due to funding constraints and overall attendance at the meeting. The number of approved applications went slightly above 25 for some regions because it was assumed that some participants would cancel or not show. Because a significant number of individuals did cancel or fail to show up, the actual number of attendees was 107.

Table 2: Application Results by Region

Applications	Central	Eastern	Northern	Northwest	Southwest	Total
Received	52	40	27	37	22	178
Denied	22	10	1	9	0	42
Approved	30	30	26	28	22	136
Cancellations	4	3	2	1	3	13
No-Shows	1	3	3	7	2	16
Expected	26	27	24	27	19	123
Attendees	25	24	21	20	17	107

Honorariums also became a point of debate in recruiting HIV-infected and affected participants. Some felt honorariums should not be offered, while others wanted the honorariums. The group voted on the option of not putting the honorarium on the flyer, but instead identifying it on the application with a stipulation that the participant would only receive the honorarium if they actively participated in the process. In addition, travel reimbursement, hotel and food were also provided for infected and affected participants.

- **Evaluating the SCSN Process:** The steering committee also focused on evaluating the SCSN process. The last SCSN, although providing information related to barriers and needs, did not provide the strategies and overarching themes needed for program planning. To address this issue, the steering committee remained focused on providing a highly-structured program, but also on evaluating the process. An evaluation form was developed, revised and finalized by the steering committee. The evaluation form had some general questions regarding demographics, and some questions oriented to specific agenda items. In addition, comment areas were provided to allow attendees to write down any thoughts they felt were appropriate.

Overall, the steering committee faced many challenges in developing the 2004 SCSN. However, recognizing the need and urgency to have a process that was more proactive in strategizing how to fill gaps and need, the steering committee came together through debate and compromise. The end result was a two-day consumer driven process resulting in proactive goals and strategies to guide the comprehensive planning process.

#### *The Day of the Event* **Participation<sup>15</sup>**

One hundred and seven attendees from the five health regions, seventeen facilitators and five VDH staff attended the SCSN held in Charlottesville, VA on June 17 and 18, 2004. A total of 77 attendees were documented as participating in the pre-meeting discussion groups, however this number included facilitators and recorders who were not asked to identify HIV status. Table 3: SCSN Attendees' Demographics shows the diversity of the SCSN participants.

Table 3: SCSN Attendees' Demographics

Demographic	Central	Eastern	Northern	Northwest	Southwest	Total	
Race and Ethnicity							
Black	14	20	9	7	10	60	56%
White	9	4	11	12	7	43	40%
American Indian	2	0	0	0	0	2	2%
Hispanics	0	0	1	0	0	1	1%
Others	0	0	0	1	0	1	1%
Gender							
Female	14	9	11	8	8	50	47%
Male	8	15	10	12	9	54	50%
Transgender	3	0	0	0	0	3	3%
Age							
Under 22	0	0	0	0	0	0	0
22-31	0	1	0	2	0	3	3%
32-40	6	4	3	4	5	22	21%
41-50	7	12	7	7	6	39	36%
51-60	7	4	9	6	4	30	28%
61 and Over	2	0	0	0	0	2	2%
Not available	3	3	2	1	2	11	10%

The participants reflected the epidemiology (see epidemiology section for more details) of HIV/AIDS in Virginia with the majority of participants being black (56%), male (50%) and between the age of 41-50 (36%). There were several transgender individuals present from the

<sup>15</sup> This section was adapted from the Virginia Department of Health status report providing a summary of the attendees. The author would like to acknowledge the VDH staff that put this information together to make this section of the report possible.

Central Region, which could reflect the increased outreach to this high risk population. Although attendees were older bringing the 41-60 perspective (together representing 64% of participants), new HIV infections are occurring in the 32-40 range (which only represented 21% of the participants). Future SCSN steering committees may want to think about ways to recruit more infected and affected individuals representative of youth and young adults.

Recruitment for the 2004 SCSN successfully reached the goal of having over 50% participants comprised of HIV-infected and affected individuals. Table 4: SCSN Attendees Relationship to HIV/AIDS shows that 66% of the participants were HIV-infected/affected and included a number of HIV/AIDS infected individuals who were also providers (n=10, 9%).

Table 4: SCSN Attendees' Relationship to HIV/AIDS

Demographic	Central	Eastern	Northern	Northwest	Southwest	Total	
Relationship to HIV/AIDS							
Health Care Provider	2	1	4	2	2	11	10%
HIV/AIDS Infected & Provider	4	5	0	1	0	10	9%
HIV/AIDS Infected/Affected	12	13	14	10	12	61	57%
Consortium Lead Agency	1	1	1	1	2	6	6%
Public Agency	3	1	2	1	0	7	7%
Case Manager	2	2	0	1	1	6	6%
Support Services	1	0	0	2	0	3	3%
Other	0	1	0	2	0	3	3%
Receive or Provide Services From (duplicated counts, consumers could receive services from more than one Title)							
RW Title I	9	8	8	7	5	37	35%
RW Title II	15	16	13	7	6	57	53%
RW Title III	2	4	1	6	0	13	12%
RW Title IV	1	1	1	3	0	6	7%

Fifty-three percent of participants had received services funded by Title II. This is consistent with Title II funds being available statewide. Of interesting note, several people in Central (n=9) and Southwest (n=5) stated they received services under Title I; however no Title I funds are available for these areas. This could reflect movement of some HIV-infected individuals from the three Title I regions, Eastern, Northwest and Northern, to areas not eligible for those funds. Similarly, 5 individuals from Eastern reported receiving/providing Title III and IV funded services when these funding streams are not available in that region. Future regional needs assessments may want to explore how many of their clients have received services from other health regions and why. However, it is also possible that clients simply do not understand which Title is paying for their care.

## Pre-Meeting HIV-infected/Affected Discussion Groups

The pre-meeting discussion groups were held from 7:00 pm-9:00 pm at the Holiday Inn in Charlottesville, VA. The pre-meeting was facilitated by steering committee members. A total of 77 attendees were documented as participating in the pre-meeting discussion groups, however this number included facilitators and recorders who were not asked to identify HIV status. The steering committee worked together to identify key questions they wanted consumers to respond to prior to the main SCSN meeting. To provide more opportunity for individuals to talk, each group had 8-12 individuals representing the various health regions in Virginia. Appendix C: Pre-meeting Discussion Group Questions and Client Group Guidelines are attached. The questions covered such areas as:

- Describe the quality of HIV services received in the last year.
- How do you feel about the amount of services you received?
- A discussion on the provider/patient contact.
- Describe your access to services and barriers.
- What events in the last year affected how you received services? and
- What are some solutions to the barriers listed previously?

Participants gave mixed comments related to the quality of care they've received from their Ryan White providers. For some, they stated their services were "excellent," "sensitive," and "overall, generally good." On the other hand, clients blamed red tape and provider insensitivity for negative experiences. One participant stated, "Although there have been lots of advancements in treatment, at the same time, there are increasing barriers for mothers. They lack treatments for kids."

**Personal Perspective:** Several participants arrived at the pre-meeting very emotional, tearful and upset. During the discussion groups, they shared their story. "Someone on a waiting list for medical care passed away just two days ago. Why do people have to wait for treatment?"

- SCSN pre-meeting participant

Quality of care issues intertwined with gaps in services as the discussions continued. Other vital factors related to gaps in service and the quality of care provided to participants included:

- Providers, especially among the "young doctors" "need more cultural sensitivity training." Clients are not comfortable sharing their HIV status, especially in the Emergency Room. Communication between providers and patients needs improvement.

**Personal Perspective:** Services that are culturally competent are not there. Service providers are not respectful. MDs are reluctant to treat you if you are HIV+.

- SCSN pre-meeting participant

- There is a lack of privacy and confidentiality. When providers did take you to a private room, “you were forgotten about” and “felt isolated.”
- There is still a lot of stigma and discrimination from medical and support providers, family, friends and community members. “People still refuse to learn about HIV.”
- Rural areas are still not offering as many services, mostly due to limited funding.
- “There is a lack of compassion from case managers.” Clients reported that case managers are not trained, lack knowledge of both available services and on how to navigate the system.
- Gaps in insurance. Who will help with co-pays and deductibles? Who is the “payer of first resort” if Ryan White is the payer of last resort?
- There is a need for assistance that covers dual diagnosis, co-infection and medication adherence.
- “Newly diagnosed don’t know where to start.”

**Personal Story:** “My providers are fantastic. Medical has been great. Can’t complain about that. My only problem is that my medical case manager left without any notice and no one to replace her. There was no transition to a new case manager.”  
- SCSN pre-meeting participant

Case management seemed central to low quality services and gaps. Although some case managers were praised for being compassionate, effective and resourceful, many of the participants identified case management services as low quality.

Critical events in the past year said to affect the quality and availability of HIV care included contract disputes and lack of contract monitoring in one of Virginia’s Health regions impacting Title I’s ability to fund needed services. The contract disputes led to agencies either closing their doors or delaying services. Other circumstances impacting care included not having child care or other ancillary services available and the lack of interpreters for HIV-infected and affected individuals.

Some strategies from participants provided momentum for self-efficacy for others. Participants stated they needed to be persistent in finding a good provider and work at open communication with their physician. In addition, they stated “you had to be involved in your own case planning” and draw from the various support groups available. “It’s a time when HIV-infected and affected people need to educate themselves and take responsibility for their own care,” stated another. External strategies included having more training for case managers, locating additional funding to fill resource gaps, train more providers in HIV care, utilize case finding to help link people to care, and increase ancillary service volunteers.

Overall, the pre-meeting discussion groups were successful in providing the safe and compassionate environment needed for HIV+ infected and affected individuals to come together and share their experiences. It also provided time for participants to gain an understanding for the process awaiting them the following day. The pre-meeting groups set the stage for infected and affected individuals to begin thinking about how the experiences shared that evening could be translated into the SCSN process.



## The SCSN Day

Pre-registered participants awoke the next day to enjoy a continental breakfast and the opportunity to network with other participants.

SCSN AGENDA	
9:00-10:00	Registration and Continental Breakfast
10:00-10:20	Welcome and Overview of the 2004 SCSN Meeting
10:20-10:45	HIV/AIDS Epidemiological Trends
10:45-11:00	Break
11:00-12:30	Small Group Discussion Session 1
12:30-1:00	Lunch
1:30-3:00	Small Group Discussion Session 2
3:00-3:15	Break
3:15-4:00	Small Group Discussion Session 3
4:00-4:15	Conclusions and Evaluations
4:15	Adjournment

The morning session provided participants with an overview of the SCSN process by Kathryn Hafford, Deputy Director of the Division of HIV, STD, and Pharmacy Services, VDH and a snapshot of HIV/AIDS epidemiology in Virginia by Jeff Stover, Director of Health Informatics and Research, Division of HIV, STD, and Pharmacy Services, VDH. Time for didactic presentations was limited to allow more time in the small group breakout sessions. The breakout sessions focused on the top eight needs in the state (as determined by regional needs assessments). The needs were divided between the first and second sessions. The first session focused on health related needs (dental care, medication, and primary medical care) and the second session focused on support related needs (transportation, emergency financial assistance, help receiving government benefits and case management). Facilitators received guidance on how to conduct each session. Barriers and gaps in service that prevent these needs from being met were identified along with solutions to address them.

### SCSN Breakout Sessions Outline

#### Session 1 Only

- What made you participate in the SCSN meeting?
- Establishing ground rules for discussion.

#### Session 1 and 2

- How do these needs match your experience?
- What barriers get in the way of getting these needs met?
- Ranking the barriers.
- What services are missing?
- What would make it easier for you or your clients to get what you (or they) need?

#### Session 3

- What repeating issues or recurring themes have you come up?
- What common threads connect the 8 needs we discussed in session 1 and 2?
- Formulate one or two broad goals that would address the cross-cutting issues.

Small group discussions built upon the pre-meeting discussions. Facilitators encouraged a constructive approach by explaining that while an individual's past experiences with services may be important as an example or to help another participant to understand a need or barrier, the discussion was not the time to complain about a specific service provider. The third session had participants focusing on common threads, themes and cross-cutting issues that fell out of the discussion during the first two sessions. This final session looked at broad goals that VDH and the steering committee could use for future service planning. Appendix D: Guidelines for Facilitating Small Group Discussion Sessions details the facilitator's instructions.

### SCSN Evaluation

The analysis of participant evaluations was performed by Safere Diawara, Contract Monitor, VDH. The following section is based on this analysis. The full report is located in Appendix E.

#### Evaluation of the June 17<sup>th</sup> Pre-Discussion Group<sup>16</sup>

There were 77 attendees at the pre-meeting discussion group and 66 evaluations were returned. The first six close-ended questions were rated using a scale with the following four response options: strongly agree, agree, disagree,

On the flip side: "I felt this meeting was much too unstructured and several individuals used up valuable time in discussing personal data, which was often unrelated to the subject at hand."

"This meeting helped prepare me for the SCSN meeting, gave me a better insight on subject matters."

and strongly disagree. A majority of those who filled out evaluations strongly agreed (70%) and agreed (29%) that they felt they were able to express their feelings and needs. Ninety-nine percent strongly agreed or agreed that the

<sup>16</sup> The evaluation report was provided by the Virginia Department of Health.

meeting was well organized and 100% strongly agreed or agreed that the facilitators were receptive to their comments. More than 95% of the respondents felt the Pre-meeting Discussion Group was useful, the content of the meeting was consistent with their expectations, and that by the end of the session, they were ready to participate in the SCSN meeting.

### **Evaluations of the June 18<sup>th</sup> SCSN Meeting:**

Out of the 107 attendees, 100 evaluations were received. The first seven questions were rated using a scale with the following four response options: strongly agree, agree, disagree, or strongly disagree.

“Morning session was very interesting because a lot of wonderful input was given.”

Ninety-eight percent of the respondents strongly agreed or agreed that during the SCSN morning session, SCSN objectives and process were clearly explained and the report from the pre-meeting discussion groups was clear. Ninety percent of those who filled out evaluations indicated that the epidemiology data was presented in a way that they could understand.

Wonderful opportunity for all involved to voice feelings/opinions on the topics- Great work!

Ninety-two percent of the respondents agreed that the breakout sessions were well organized, the facilitators were well prepared, and that participants were able to share their point of view. There was a mixed response to the question related to the time allotted to each

session. Seventy-seven percent of respondents felt that enough time was allotted to each session, while 20% of respondents disagreed.

Overall, 85% of respondents felt the publicity was effective in recruiting representative participation and 88% felt that the SCSN objectives were achieved. Overall, 88% felt satisfied with being able to participate and fully express their opinion.

Suggestions: The majority felt the pace of the meeting was uncomfortable. Next year, the committee may want to think about slowing down the pace some.

The evaluations have provided a wealth of positive feedback as well as some important constructive criticism. This information, along with the many comments the steering committee received, will assist the SCSN committee with planning future meetings.

### **Writing the SCSN Report**

Due to personnel vacancies at VDH, the writing of the SCSN was contracted out to the Survey and Evaluation Research Laboratory (SERL) at Virginia Commonwealth University. This report consists of original writings by Laurie Safford, senior research associate and steering committee member, and components of reports, minutes and summaries authored by VDH staff. The report has been reviewed by and additional input received from the SCSN Steering Committee and the Ryan White Subcommittee of the Virginia HIV Community Planning Committee.

## EPIDEMIOLOGICAL PROFILE OF VIRGINIA

### Notable Fact:

Since 1989, 15,466 cases Of HIV have been reported in Virginia.  
(VDH, 2004)

The U.S. Census Bureau (2003) estimates Virginia's population at 7,293,542 residents. According to the 2004 Epidemiological Profile by VDH, "Research shows that sexually transmitted diseases are primarily urban and most problematic in areas of high population density. Indeed, almost 80% of all people in Virginia live in one of eight Metropolitan Statistical Areas (MSA) and 90% of the living HIV/AIDS cases as of 12/31/2004 were reported from these areas (page 7)."<sup>17</sup> Virginia faces many challenges in providing HIV prevention and care services given the geographic diversity of the state. Outside of the eight MSAs lie large areas of mountainous, rural and low population density areas where HIV/AIDS incidence may be low, but service availability is limited. Four urban areas, Alexandria, Arlington, Richmond and Norfolk share current HIV and AIDS incidence higher than their overall share of the population.<sup>18</sup> Table 5: Persons Living with HIV Infection Only as of December 31, 2003 in Virginia shows the number of reported HIV cases by region and demographic.

Table 5: Persons Living with HIV Infection Only as of December 31, 2003 in Virginia<sup>19</sup>

Demographic	Northern		Eastern		Central		Northwest		Southwest		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
<b>Gender</b>												
Male	1544	70.5	2174	70.7	1627	71.5	347	69.4	434	68.2	6126	70.6
Female	647	29.5	901	29.3	648	28.5	153	30.6	202	31.8	2551	29.4
<b>Total</b>	2191		3075		2275		500		636		8677	
<b>Race/Ethnicity</b>												
White	738	33.7	723	23.5	498	21.9	251	50.2	286	45.0	2496	28.8
Black	1208	55.1	2203	71.6	1696	74.5	226	45.2	333	52.4	5666	65.3
Hispanic	186	8.5	95	3.1	55	2.4	19	3.8	11	1.7	366	4.2
Asian/Pacific Islander	36	1.6	17	0.6	4	0.2	2	0.4	2	0.3	61	0.7
Alaskan/Native American	1	0.0	6	0.2	1	0.0	0	0.0	0	0.0	8	0.1
Other/Unknown	22	1.0	31	1.0	21	0.9	2	0.4	4	0.6	80	0.9
<b>Total</b>	2191		3075		2275		500		636		8677	

\*Due to rounding up to the tenth decimal place, percentages may not equal 100%.

<sup>17</sup> Virginia Department of Health (2004 DRAFT). Epidemiology Profile HIV and AIDS I Virginia 2004. Prepared by Division of HIV, STD and Pharmacy Services, Richmond Virginia.

<sup>18</sup> Ibid.

<sup>19</sup> Ibid

As Table 5 demonstrates, HIV infection is more common among males (71%) and blacks (65%) except in the predominately rural Northwest region of the state where there is a difference of 50% white and 45% black. Hispanic and Asian Pacific Islander populations are more affected in the Northern and Northwest region. This could be due to the close proximity to Washington, D.C. and higher numbers of migrant workers in those areas. Central is also beginning to experience increases in HIV infection among Hispanic individuals with 55 people of this ethnicity reported as living with HIV in 2003.

Looking at demographics of people living with AIDS as of Dec. 31, 2003 (See Table 6), shows again the majority of individuals are male (77%) and black (59%). In the Northern, Northwest and Southwest regions whites and blacks have even distribution of cases, while Eastern and Central have more blacks (69% and 75%) living with AIDS. Overall, "Virginia has a significantly higher proportion of blacks living with HIV and significantly lower proportions of whites and Hispanics living with HIV than the national average indicates (national average is 53% black, 37% white and 9% Hispanic).<sup>20</sup> The prevalence rate for Persons Living with HIV infection only is 119.0 per 100,000 and prevalence rate for Person Living with AIDS is 98.6 per 100,000.<sup>21</sup>

Table 6: Persons Living with AIDS as of Dec. 31, 2003 by Region<sup>22</sup>

Demographic	Northern		Eastern		Central		Northwest		Southwest		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
<b>Gender</b>												
Male	1787	80.6	1657	74.4	1248	77.9	433	77.7	444	75.3	5569	77.4
Female	430	19.4	570	25.6	355	22.1	124	22.3	146	24.7	1625	22.6
<b>Total</b>	2217		2227		1603		557		590		7194	
<b>Race/Ethnicity</b>												
White	980	44.2	612	27.5	363	22.6	266	47.8	295	50.0	2516	35.0
Black	967	43.6	1537	69.0	1203	75.0	260	46.7	283	48.0	4250	59.1
Hispanic	219	9.9	65	2.9	32	2.0	27	4.8	9	1.5	352	4.9
Asian/Pacific Islander	46	2.1	10	0.4	3	0.2	4	0.7	3	0.5	66	0.9
Alaskan/Native American	1	0.0	1	0.0	1	0.1	0	0.0	0	0.0	3	0.0
Other/Unknown	4	0.2	2	0.1	1	0.1	0	0.0	0	0.0	7	0.1
<b>Total</b>	2217		2227		1603		557		590		7194	

\* Due to rounding up to the tenth decimal, all percentages may not equal 100%.

<sup>20</sup> Ibid

<sup>21</sup> Ibid

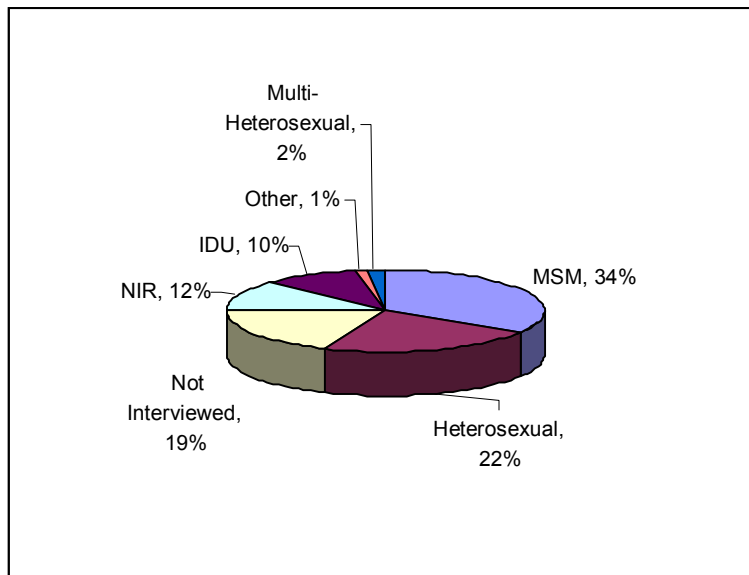
<sup>22</sup> Ibid

**Notable Fact:**

“From 1989-2003, the average age of HIV diagnosis increased from 31.8 years to 35.2 years. The average age of AIDS diagnosis increased from 36.2 years to 39.6 years.” (VDH 2004)

Between 2001 and 2003, men who have sex with men (MSM) accounted for the majority of HIV transmissions (34%), followed by heterosexual transmission (22%). Unfortunately, transmission risk was not identified or reported for a significant number of cases (No Identified Risk, NIR 12% and Not Interviewed 19%). Transmission by injection drug use (IDU) ranked 5<sup>th</sup> with 10%. Chart A: HIV Cases by Risk Category for 2001-2003 in Virginia illustrates risk categories.

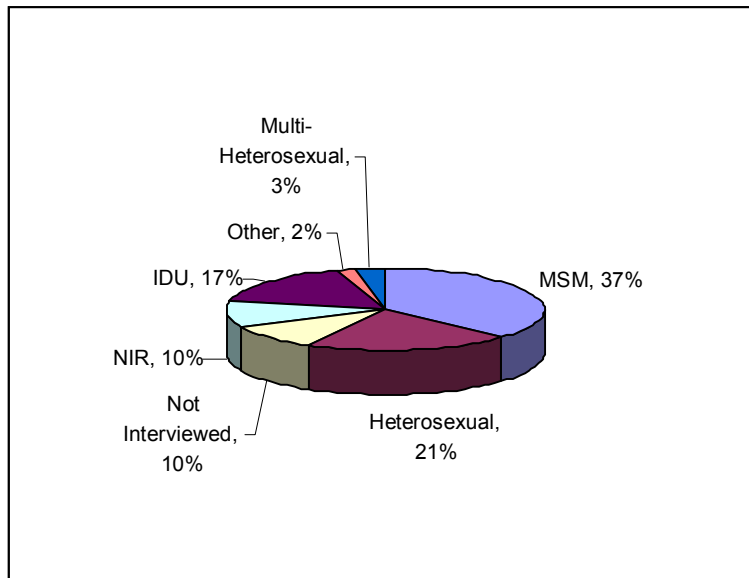
Chart A: HIV Cases by Risk Category for 2001-2003 in Virginia<sup>23</sup>



In contrast, Chart B: AIDS Cases by Risk Category for 2001-2003 in Virginia demonstrates that although MSM (37%) and Heterosexual (21%) remain the top two transmission modes, IDU transmission increased to 17%.

<sup>23</sup> Ibid

Chart B: AIDS Cases by Risk Category for 2001-2003 in Virginia<sup>24</sup>



Some differences in transmission risks are identified when examining both race and risk together. For example, in men with HIV infection, whites more frequently identified a transmission risk of MSM than blacks, while HIV+ black men more frequently reported other risks, specifically IDU and heterosexual transmission. In addition black men were more likely to have no identified risk category (NIR), and to not be interviewed.

**Notable Fact:**

“For at least the past five years, black females represented the largest proportion of heterosexual transmission reports followed by black males, white females, and white males.” (VDH 2004)

Participants at the 2004 SCSN (disregarding risk category since that information was not collected) demographically reflected the race and gender breakdown of overall HIV/AIDS in Virginia. In regards to age, Virginia is showing an older population with HIV infection. This could be one reason why youth and young adults (18-31) were not represented to the degree that 31 year olds and older were at the SCSN.

## REGIONAL NEEDS ASSESSMENTS

VDH took each of the five regional Ryan White Title II Consortia and the Ryan White Title I Greater Hampton Roads Planning Council Needs Assessments and combined them to determine the top eight needs across the state. First, each region sent VDH its top eight identified needs. A point value was given to each need based on how it ranked in each regional needs assessment (8 pts for the top ranked need, 7 for the 2<sup>nd</sup> ranked, 6 for the 3<sup>rd</sup> ranked and so on). The totals were then added up and averaged. On a scale of 1 to 8, the top eight needs identified were:

<sup>24</sup> Ibid

<b>Service</b>	<b>Score</b>
Dental Care	6.33
Medication	3.83
Transportation	3.00
Emergency financial assistance	2.83
Help w/ government benefits	2.50
Food	2.33
Primary medical care	2.17
Case Management	1.83

The other critical needs listed on the needs assessments and mentioned during both the pre-meeting discussion groups and the SCSN workgroups included:

- Housing/homelessness
- Need for more case managers and training
- Insurance
- Better quality of care
- Culturally competent care
- Interpretation Services
- Benefits to cover gaps for employed individuals
- Consistent agency policies
- Funding
- Better communication
- Support groups
- Employment training/job training
- Mental health
- Eye care
- Nutritional support
- Clothing
- Help understanding resources and the system
- Household helpers
- Substance abuse treatment
- Non-traditional hours for care
- Transitional services for incarcerated individuals

## **RESULTS OF THE SCSN MEETING**

### **Barriers and Gaps**

The small group discussions first focused on medical services then turned to support services. Participants found that many of the same barriers and gaps crossed over the various services. The ten discussion groups developed and prioritized the barriers and gaps for the top eight needs. This report will focus on providing an overview of the four major themes that were most prominent during the discussions and then present a group level analysis.<sup>25</sup>

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<sup>25</sup> Each discussion group recorded their responses on a worksheet. However, each group still recorded barriers and gaps differently; some listed under the same heading “barriers,” others broke out by each service. Therefore, it was more efficacious to pull out dominant themes for discussion in this report.



One of the top prioritized barriers and gaps was **funding**. Not only was the lack of funding for medical care and ancillary services noted, but also the inability of participants to pay deductibles, co-pays or out-of-pocket expenses for services such as dental restorative care or medications not related to HIV disease. Funding related to each of the top eight needs did take on some unique characteristics, but ultimately the participants saw the lack of financial support for services restricting infected and affected individuals from needed and/or desired services.

A second critical barrier was **accessibility**. Many participants noted that some medical care providers and support service providers had waiting lists for care. Accessibility of medication, both as it relates to potential waiting lists for ADAP (although Virginia does not have an ADAP waiting list) and ability to obtain non-HIV-related medications was also a priority barrier participants wanted to address. For many of the rural areas, availability of affordable and convenient transportation remained the primary barrier to accessing needed medical services. It was within this barrier that participants identified how the lack of funding and availability of transportation also played into their inability to access medical care and support services. Access to services was also limited by political red tape, agency politics and lack of monitoring of professional standards.

Related to professional standards, SCSN participants noted their frustration about the **need for more knowledgeable and culturally competent providers** (both medical and support service providers). Participants saw the lack of cultural competency and skills training as a barrier to receiving quality care. Another level to this barrier was the need for Spanish-speaking providers and available translation services. Some noted that they had been denied support services (such as food) because of their HIV status. Stigma was one of the most mentioned barriers for preventing access to both medical and support services.

The most discussed barrier/gap among the groups was **case management service** itself. Participants stated that the quality of case management services was affected by high case loads, resulting in case managers being overworked, and experiencing burnout. They also identified that case managers need a consistent statewide training and certification process followed by monitoring of performance against the state case management standards. Other critical issues contributed to case management being listed as a barrier and service gap include:

- Not having enough skilled and knowledgeable case managers;
- Staff turnover;
- The lack of cultural competency and sensitivity;
- The lack of knowledge about available services and how to work the system;
- Lack of client bill of rights; and
- Inappropriate behavior.

The ten groups wrote up the results of their barrier discussion related to medical services (primary care, medication, and dental) separately from barriers identified for support services (case management, transportation, emergency financial assistance, food, case management, and assistance with government benefits).<sup>26</sup> Given the extensiveness of the list provided under each section, similar categories were collapsed.

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<sup>26</sup> The last group also listed barriers and through examining their list, were able to separate between medical and support barriers.

## Medical Services (Medication, Dental and Medical Care)

Table 7: Barriers for Medical Services illustrates the barriers identified by 20% (2 of the 10 groups) or more in the medical category.<sup>27</sup> Barriers applicable to medical services in general are listed under Medical Care. Lack of funding was the primary barrier listed by consumers and providers at the SCSN. However, this barrier exceeds beyond just the need for more money and encompasses specific barriers such as inability to pay for over-the-counter medications and co-pays and working within insurance restrictions. Two groups identified Ryan White procedures as not being provider-friendly and contributing to a shortage of providers.

Another major issue for consumers was waiting lists and lag time between receiving lab work and having a medical appointment. Some reported wait times up to several weeks or more for a primary care appointment. For dental care, the barriers were the same regarding funding, wait times and the need for more experienced dental providers. In addition, several groups identified the need for dental coverage to go beyond emergency work, and cover preventative care and dental problems not related to HIV.

Table 7: Barriers for Medical Services

Categories	% Groups
<b>Medication</b>	
Limited drug formulary, access to drugs and drug availability	50%
Funding (including the lack of money for drugs and over-the-counter medications, the high cost of drugs, competition and profit margins that drive drug costs up	40%
<b>Dental Services</b>	
Limited coverage, covering emergency services only, insurance issues, decrease in RVV funds for dental	40%
Dental problems not HIV-related	20%
Stigma, fear of treating HIV patients, lack of HIV knowledge	20%
Shortage of providers/ Ryan White procedures not provider-friendly	20%
Transportation to dental	20%

<sup>27</sup> Groups were also asked to rank the barriers. However since not all groups did this, there was no way to rank the most important barriers for the groups. Instead, frequently mentioned barriers across the groups were done.

<b>Medical Care</b>	
Lack of funding, money needed to cover co-pays, insurance restrictions	70%
Lack of HIV education for providers and clients, need to compensate providers for training time	60%
Transportation to medical appointments	60%
Shortage of providers/Lack of experienced providers	60%
Waiting lists, lag time between labs and appointments, need for 24 hour service	50%
Location of medical services including problems with rural areas and “turf issues”	40%
Cultural competency, language, cultural sensitivity	30%
Availability of support services like SA treatment and housing	30%
Stigma	20%
Bureaucracy	20%
Failure of agencies to collaborate	20%
Need for non-traditional hours	20%

When analyzing support services on a group level, some barriers listed were more related to overall support than specific to food, case management, emergency financial assistance, assistance receiving government benefits and transportation. Table 8: Barriers for Supportive Services illustrates the diversity of barriers clients experience when attempting to receive support services. In an effort to bring focus to the more common barriers, those that were listed by 20% of the groups or more are listed.

Table 8a: Barriers for Supportive Services

<b>Listing</b>	<b>% Groups</b>
<b>Support Services in General</b>	
Need for other funding sources	40%
Lack of communication and coordination between agencies	30%
Lack of information on available services	30%
Lack of client-centered services	20%
Location, especially rural areas	20%

Other barriers mentioned included how clients felt like they needed to implore providers for services, the lack of cultural competency and the need for more support groups. Similar barriers run through when breaking out the support services.

Table 8b: Barriers for Support Services continued

<b>Listing</b>	<b>% Groups</b>
<b>Emergency Financial Assistance (EFA)</b>	
Conflicting definitions of what EFA is, bureaucracy and need for consistent eligibility criteria	30%
Need for additional funding	20%
Assistance is untimely and costly	20%
Lack of collaboration between agencies and in-house fighting	20%
Lack of understanding regarding assistance	20%
<b>Food Assistance</b>	
Need for nutrition education for consumers	30%
“Turf issues”	20%
Funding concerns including lack of access to non-RW funds	20%
Receiving nutritious, non-expired food	20%
Unaware of available resources	20%
Need for convenient supermarkets, location and hours of operation of food banks	20%
<b>Assistance Receiving Government Benefits</b>	
Need for education and information about benefits	40%
Lack of benefits available to employed consumers, program limitations	20%
Complex application forms	20%
Eligibility requirements (familial status, socio-economic status, legal status/immigration)	20%
Policy inconsistency and bureaucracy	20%

Table 8c: Barriers for Support Services continued

<b>Listing</b>	<b>% Groups</b>
<b>Case Management</b>	
Lack of case managers	30%
Burnout	30%
Need for education, training and certification	30%
Need for consistent standards and definitions	30%
Case management in general is a barrier	20%
Cultural sensitivity	20%
Lack of triaging clients	20%
Staff turnover	20%
Unprofessional behavior	20%
Lack of case manager/client communication, need for client evaluation	20%

The ten groups were also asked to identify gaps in services. Only five (50%) listed gaps, while others included their gaps in the barriers sections. A few groups did separate barriers out by service type, but most of the items listed ran across both medical and supportive services. Table 9: Service Gaps list the gaps in order of how many groups identified them.

Table 9: Service Gaps

<b>Listing</b>	<b># of Groups</b>
<b>Service Gaps</b>	
Lack of or limited education for providers and consumers	4
Lack of resources	3
Eligibility, confused about eligibility, conflicts in eligibility	3
Reimbursement times for providers are long, RVW not provider friendly	3
Transportation (drop patients at the front door, need to see multiple providers in a day, need for mass transit)	3
Need for standardized procedures	3
Transitional housing, homelessness, low-income housing	3
Pre-release programs for incarcerated individuals	3
Lack of providers (dental, HIV specialists, case managers)	2
Other illness resulting from HIV meds not covered	2
Lack of interpreters	2
Inadequate Emergency Assistance	2

Other gaps in services mentioned by the five groups included concerns over waiting lists, running out of medication before the next primary care appointment, lack of HIV-specific food banks and pharmacies, clients being treated like they are in an assembly line, the need for more consumer empowerment, and access to centralized and consistent information. During group

discussions, many realized that service barriers and gaps were interconnected; one affecting the other. In future planning, examination of barriers and gaps on a universal level may be warranted in addition to looking at specific issues.

## **Service Strategies**

Service strategies recommended by SCSN participants could be divided into system-level strategies and consumer-level strategies.

### **System Level Strategies**

- Identify a consistent way to triage HIV-infected and affected individuals and base service on the individual's level of need;
- Increase provider training especially for case managers. Establish certification process, cultural competency and other trainings for case managers. Update knowledge on government benefits and alternatives to disability (i.e. employment);
- Monitor service providers;
- Increase collaborative efforts between agencies;
- Increase the volunteer force to assist with delivering meals, child care, transportation;
- Develop sliding scale fees for non-covered services and non-HIV-related medications;
- Identify and utilize alternative funding sources;
- Standardize and/or centralize services across Ryan White CARE Act Titles;
- Shorten reimbursement times and provide service providers incentives; and
- Provide mobile medical services to hard-to-reach areas.

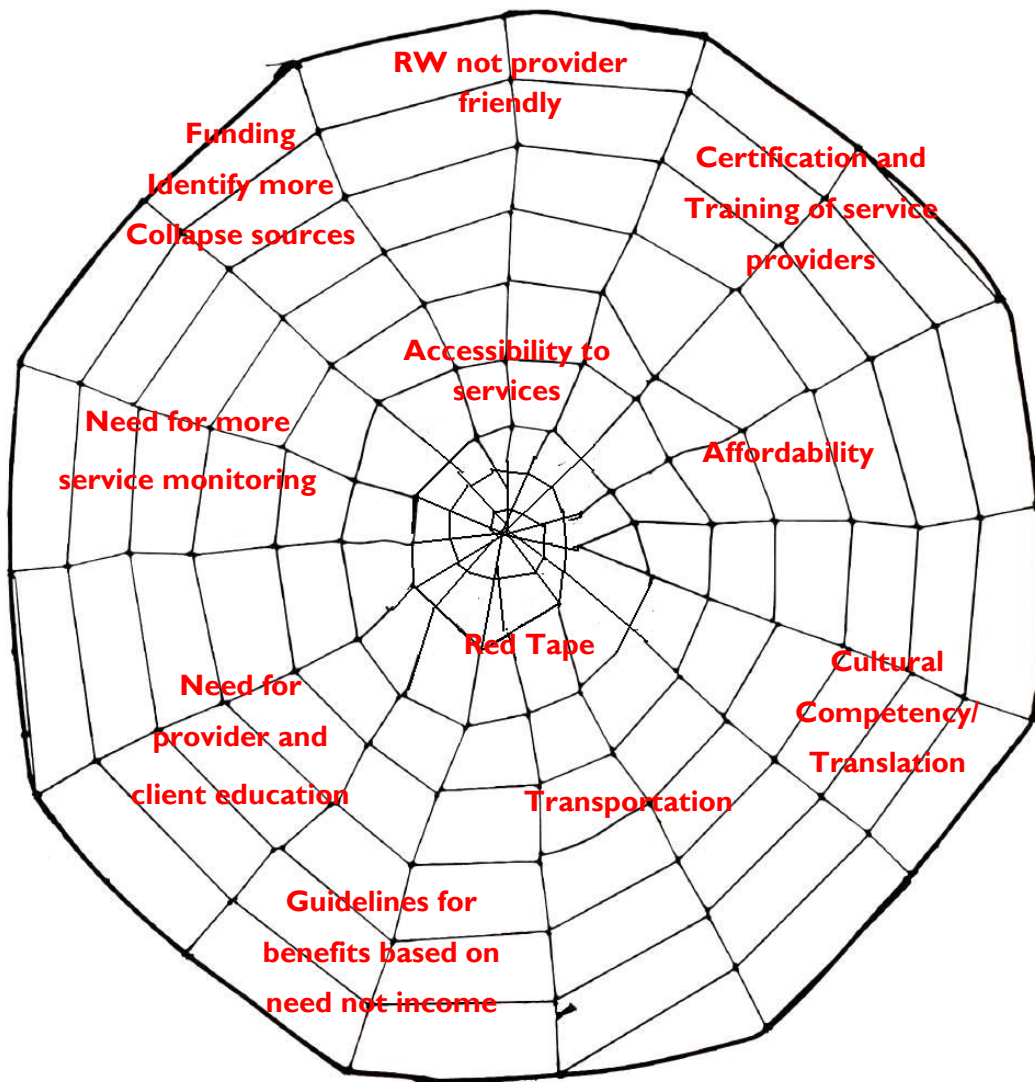
### **Client-level Strategies:**

- Clients must empower themselves and others;
- Clients can increase their participation in the treatment plan;
- Participate in client advocacy;
- Attend consumer education classes (e.g. on nutrition, medication, budgeting). Offering more educational and training opportunities to consumers may also be viewed as a system-level strategy;
- Develop standards for client utilization of services;

Providers and HIV-infected and affected individuals came together to develop strategies that could enhance the current service system. Reducing stigma became both a system-level and client-level strategy as participants advocated for more public HIV education. It was stated that through the collaboration of all individuals, the quality of HIV services can be enhanced even during times of funding decreases.

## **Crosscutting Issues/Themes**

As briefly mentioned in this report previously, several overarching themes and issues arose from the small work group discussions. Interwoven together, these issues illustrate a weave of how the lack of consistency, collaboration and communication can cause barriers and gaps in an HIV service system.



This depiction of the interrelatedness of barriers, gaps and strategies serves to illustrate how a change in one component may create change in the others, both negatively and positively. This concept is critical to developing an effective comprehensive plan that addresses the issues identified during the SCSN process.

## Goals

Different from the 2000 SCSN, the steering committee requested that each discussion group develop one or two overarching goals. Many of these goals coincided with the overarching themes and barrier discussions from the groups. Some groups formulated very articulate goals, while others provided thematic listings. Goals are presented here as articulated by the participants and categorized to the primary barriers and service gaps identified earlier:

## **Funding**

- 1) Develop a process to prioritize services that are funded.
- 2) Identify and implement strategies to impact funding sources and policy makers and diversify funding sources.
- 3) Base employed clients' benefits on net income, expenses and family size.
- 4) Increase funding of transportation services, giving priority to underserved communities, including rural areas.

## **Accessibility**

- 1) Improve providers' ability to navigate the system to get Medicaid and other services for people living with HIV.
- 2) Create more "one stop shops."
- 3) Increase partnering of businesses and state to provide HIV services
- 4) Lobby for change in law regarding partner benefits.
- 5) Strengthen consumer network throughout the state.
- 6) Build collaborative systems and infrastructure that promotes optimal patient outcomes.
- 7) Empower and educate consumers to become advocates for policy and service change.
- 8) Increase self-advocacy by clients accessing services to ensure a client-centered approach to care and treatment.
- 9) Promote statewide advocacy for care and treatment funding and medications, including non-ADAP medications.

## **Increasing Knowledgeable and Culturally Competent Providers**

- 1) Develop quality indicators/measurement standards for evaluating services.
- 2) Evaluate different ways the state can administer ADAP.
- 3) Provide on-going cultural competency/sensitivity training to not only consumers, but to health care providers, services providers and the community at large.

## **Case Management**

- 1) Limit case manager client loads based on intensity of client needs with not more than five intensive clients per case manager.
- 2) Mandatory HIV certification for case managers, doctors, dentists and any other key providers.
- 3) Promote on-going training opportunities for providers to ensure consumers are not lost to care.

## **NEXT STEPS**

This SCSN report is intended for use by recipients of all Titles of Ryan White CARE Act funding. The wealth of information and input produced by the SCSN process will serve as the basis for development of Virginia's Comprehensive Plan. Community input and collaboration will remain central to this process. In order to maximize scarce resources, interagency collaboration across funding sources is paramount. The comprehensive planning process will look at service planning strategies that foster collaboration.



Both the SCSN Steering Committee and the Ryan White Subcommittee of the Virginia HIV Community Planning Committee will serve in an advisory capacity as the plan is developed. The ADAP Advisory Committee will be utilized as needed for input on issues specific to that program. VDH has mobilized additional staff resources to facilitate the planning process through its newly created HIV Health Care Planner position. The planner will work to optimize community input and collaboration by providing continuity, a focal point for communication, and serving as a liaison with all stakeholders.

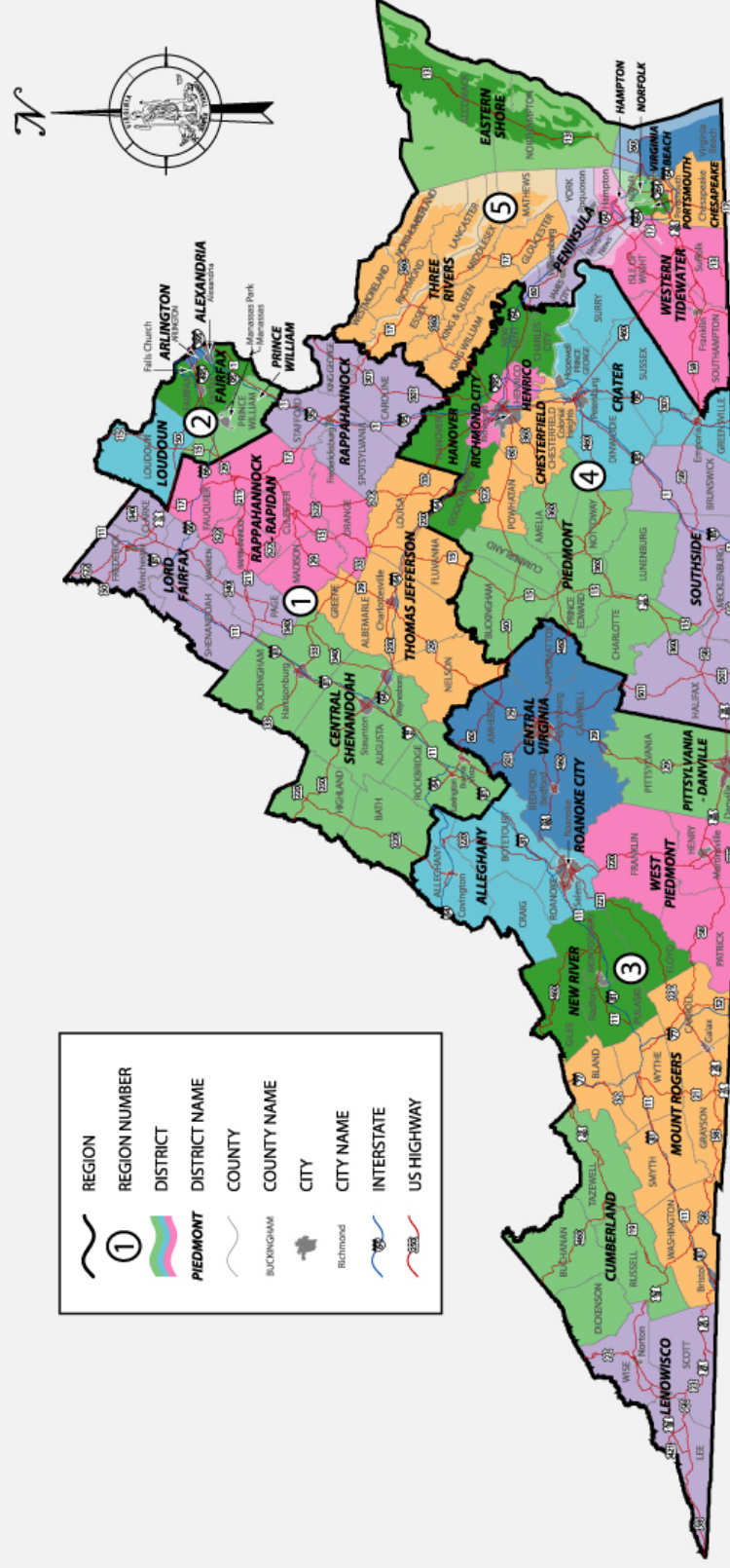
Both this SCSN report and the upcoming Comprehensive Plan will be made widely available to all Ryan White CARE Act funded grantees, providers, agencies, individuals and the community at large in hopes of highlighting the issues identified through this process.

# Appendices

**Appendix A**  
**Virginia Health Region Chart**

Appendix A: Health Region Map

# Commonwealth of Virginia - Department of Health Health Regions & Districts



**Appendix B**  
**Flyer and Application for 2004 SCSN**

**STATEWIDE  
COORDINATED  
STATEMENT of NEED  
(SCSN)  
Meeting**

**June 17-18, 2004**



**Holiday Inn-University Area &  
Conference Center  
1901 Emmet St., Route 29 South,  
Charlottesville, Virginia 22902**



## **Changing Times, Changing Lives...**

### **An Introduction to the Statewide Coordinated Statement of Need**

Sometimes people see a challenge or a problem and wonder, "What can I do to help?" If you are a person living with HIV or AIDS or someone who cares about people with HIV/AIDS, please participate in the upcoming **Statewide Coordinated Statement of Need (SCSN) Meeting which will be held June 18, 2004 at the Holiday Inn-University Area, 1901 Emmet St., Route 29 South, Charlottesville, VA, 22901.** Enclosed you will find information and an application packet for the meeting. Please take a few minutes to review the information and consider participating.

This meeting is crucial to HIV service delivery in the State of Virginia. As a condition of receiving Ryan White Comprehensive AIDS Resources Emergency (CARE) Act funding, all agencies are required to participate in the SCSN meeting. The goal is to identify and address significant HIV care issues related to the needs of people living with HIV/AIDS. Meeting participants will identify gaps in services, discuss issues and address challenges confronting HIV service provision in Virginia. In addition, the SCSN will set goals designed to guide future planning and service delivery. Following the meeting a written summary will be prepared.

The SCSN meeting will emphasize participation by individuals with HIV disease as well as include participation of service providers and public representatives. Participation by people living with HIV/AIDS is crucial to making the outcome of the meeting as relevant and useful as possible. **A special pre-meeting session for people living with HIV/AIDS is scheduled from 7:00-9:00 PM on June 17** (at the same location as the main meeting). This session will include small group discussions and will set the stage for the main meeting on the 18<sup>th</sup>.

Your participation is key to the success of these events. If you are interested in attending, please complete and return the enclosed application form. If you are unable to attend but would still like to have input, your written comments would be welcomed. Questions, comments, and completed application forms can be directed to Safere Diawara at:

Virginia Department of Health, Division of HIV/STD,  
P.O. Box 2448, Third Floor, Richmond, Virginia 23218  
Phone: 804 864-8021 Fax: 804 864-8050

## **Preliminary Agenda**

### **June 17, 2004**

**6:00-7:00 pm** Pre-Registration

**7:00-9:00 pm** Pre Meeting Discussion Groups for People Living with HIV/AIDS  
Light refreshments provided

### **June 18, 2004**

**9:00-10:00** Registration  
Continental Breakfast (Provided)

**10:00-10:20** Welcome and Overview of the 2004 SCSN Meeting **Kathy Hafford**  
Focus Group Report **Donald Walker**

**10:20-10:45** HIV/AIDS Epidemiological Trends **Jeff Stover**

**10:45-11:00** Break

**11:00-12:30** Small Group Discussion Session 1

**12:30-1:30** Lunch (Provided): Soup and Salad Buffet

**1:30-3:00** Small Group Discussion Session 2

**3:00-3:15** Break

**3:15-4:00** Small Group Discussion Session 3

**4:00-4:15** Conclusion and evaluations

**4:15** Adjournment



# STATEWIDE COORDINATED STATEMENT of NEED

**Application Deadline: May 21, 2004**

**Please return your completed application form to:**  
**Safere Diawara, Division of HIV/STD**  
**P.O. Box 2448, Third Floor, Richmond, Virginia 23218**  
**Phone: 804-864-8021 Fax: 804-864-8050**

**Space is limited. Please submit your application as soon as possible. If the meeting capacity is reached, the SCSN Steering Committee will make applicant selections. You will be notified by Safere Diawara whether you have been selected to participate by June 5, 2004.**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Are you representing any organization: ☐ YES ☐ NO If Yes, specify \_\_\_\_\_

Job Title: (if applicable) \_\_\_\_\_

Phone Number (day time): \_\_\_\_\_ E-Mail: \_\_\_\_\_

Continental Breakfast and Buffet Lunch will be provided on 6/18/04. Please indicate any special dietary needs ☐ Vegetarian ☐ Other please specify \_\_\_\_\_

Demographics:	Optional Information		
Gender:	<input type="checkbox"/> Female	<input type="checkbox"/> Male	<input type="checkbox"/> Transgender
Age Range:	<input type="checkbox"/> Under 22	<input type="checkbox"/> 22-31	<input type="checkbox"/> 32-40
	<input type="checkbox"/> 41-50	<input type="checkbox"/> 51-60	<input type="checkbox"/> 61 & over
<b>Race/Ethnicity:</b>			
<input type="checkbox"/> American Indian/Native American	<input type="checkbox"/> White	<input type="checkbox"/> Asian/Pacific	
<input type="checkbox"/> Hispanic/Latino	<input type="checkbox"/> Black/African American	<input type="checkbox"/> Other (please specify)	
<b>Relationship to HIV/AIDS:</b>			
<input type="checkbox"/> Health care provider	<input type="checkbox"/> Case manager		
<input type="checkbox"/> Support services provider	<input type="checkbox"/> Media		
<input type="checkbox"/> Public agency representative	<input type="checkbox"/> Other (please specify) _____		
<input type="checkbox"/> HIV/AIDS infected/affected			
Do you currently receive HIV-related care or services: <input type="checkbox"/> YES <input type="checkbox"/> NO If "Yes", where? _____			
Do you provide or receive services funded by any of the following? (check all that apply)			
<input type="checkbox"/> Ryan White Title I	<input type="checkbox"/> Ryan White Title II	<input type="checkbox"/> Ryan White Title III	<input type="checkbox"/> Ryan White Title IV

Special needs/circumstances \_\_\_\_\_  
HIV-infected individuals who actively participate in and attend all sessions on 6/17/04-6/18/04 are eligible to receive an honorarium in the amount of \$50.

**Please check all sessions you will attend:** ☐ Focus Group on 6/17/04, ☐ SCSN meeting on 6/18/04. (Please sign below if you would like to request an honorarium.)

Applicant Signature: \_\_\_\_\_

<b>VDH USE ONLY</b> HOPWA, DMAS, MH/SA, RW Title I, Title II, Title III, Title IV, Dental Service, Consortia
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# Travel and Hotel Registration Information

Hotel accommodations at the meeting location will be provided for the night of 6/17/04 for the following individuals:

- ☐ Facilitators
- ☐ HIV-infected individuals attending the Discussion Group meeting on 6/17/04 and the SCSN on 6/18/04
- ☐ HIV-infected individuals attending on 6/18/04 who reside more than 25 miles outside of Charlottesville and need a hotel room.

In order to request a hotel room, please mark the box above that applies to you.

**All other participants are responsible for their own accommodations.**

If you qualify for a room and would be willing to share, you have the opportunity to select a preferred roommate in advance. The roommate of your choice should be indicated on this form and submitted along with your application. If you prefer not to share, please write "not applicable" in the preferred roommate space.

The planning committee will strive to accommodate special needs. **Early registration is strongly encouraged** to help ensure that we have adequate time to fulfill such requests. **Room request deadline is May 21, 2004.**

**Name:** \_\_\_\_\_

**Preferred Roommate:** (If applicable) \_\_\_\_\_

**Special Needs/Circumstances:** \_\_\_\_\_

\_\_\_\_\_

## Rooms

**Smoking** \_\_\_\_\_

**Non-Smoking** \_\_\_\_\_

**Note:** Check in time on June 17, 2004 is 12:00 pm. Hotel accommodations will be paid for the night of Thursday, June 17, with checkout by noon on Friday. Individuals will be responsible for all incidentals such as phone calls, movie rentals, room service, etc. Any questions regarding hotel accommodations should be directed to VDH staff.

Mileage reimbursement is available to all facilitators and HIV-infected individuals. Mileage reimbursement forms will be available at the event.

**ALL OTHER PARTICIPANTS ARE RESPONSIBLE FOR THEIR OWN TRAVEL COSTS.**



Meeting facilities and hotel are handicap accessible.

**Appendix C**  
**Pre-meeting Discussion Group Questions**  
**and Guidelines**

Virginia SCSN  
Client Group Questions DRAFT 04/14/04

Thank you for joining us this evening for our pre-SCSN consumer discussion group. This evening we would like to accomplish two things. First, we would like to get you familiar with the SCSN process and prepare you for what to expect tomorrow. The second is to get your thoughts and feelings on the services you receive.

First, let's discuss the SCSN.

How many of you have been through the SCSN process before?

Would anyone like to describe what the SCSN is and why it's important for consumer involvement?

The SCSN, or Statewide Coordinated Statement of Need, brings together HIV/AIDS infected and affected individuals and other service providers to talk about and identify important issues and challenges of providing HIV services in Virginia. It is important that you are here tonight and tomorrow because you know first hand, what barriers there are to care, what programs really work for you and how providers and the Consortia can increase availability of services.

As part of your registration, you received a series of documents that you may or may not have read. I would like to take a few moments and review the information you received and see if there are any questions?

Now, let's talk a little bit about what will be happening tomorrow...

First thing tomorrow morning we will be getting an introduction to the process and some background on the HIV/AIDS epidemic in Virginia. From there, we will break into small groups. Each group will have a mix of people from all different regions and consist of both providers and consumers. A facilitator will then guide you through a series of questions regarding the eight top needs identified by the various Consortia in Virginia. (explain process of establishing need here).

The eight identified needs are:

1. Dental care,
2. Medication,
3. Transportation,
4. Emergency Financial assistance,
5. Help receiving government benefits,
6. Food,
7. Primary medical care, and
8. Case management.

(In order with 1. representing the greatest unmet need)

Taking each need, one at a time, you will identify current barriers to the service, positive experiences with the services and strategies that would assist you or people you know on accessing the service. The small group sessions tomorrow are not a time to make complaints, but a time to focus in on the problem and figure out solutions. We can only do that when we put our feelings to the side and talk about facts. We also need to understand that problems don't get solved in a day and that this is the first step in coming up with solutions. The information that is gathered during these breakouts will then be compiled and reported in the

SCSN report. The information will further be used to devise a comprehensive plan. This plan will guide Virginia over the next few years in program development to reduce barriers to the eight needs identified here.

Are there any questions with regard to what you will be experiencing tomorrow?

If there are no other questions, we would like to have some smaller discussion groups this evening for about an hour. Let's count you off, and hopefully this will give us groups of about 5-10. (count off). Now, please go to the person that is holding your number, this is your discussion facilitator for the evening.

(In the smaller groups)

**Facilitator:** Good evening. I'm \_\_\_\_\_. Let's go around and please give me your first name only and you can use a pseudo name if you like. Also, please tell us where you are from and your goals for coming to the SCSN. (go around and do introductions).

**Facilitator:** Great! Now that we are a bit more familiar with each other, let's take the next 45 minutes or so and share some personal experiences you've had with receiving HIV care. Understanding that this can get rather emotional for some of us who have had some bad experiences, I would like us to set up some ground rules. Have the participants come up with the ground rules, but be sure they include the following:

1. Please one person talk at a time;
2. Raise your hand to make a comment;
3. Be respectful to one another; we have different experiences and let us be mindful and sensitive to one another.
4. If you are disrespectful and continue to be disrespectful, you will be asked to leave the group.

Facilitator: Ok, now on to our questions.....

1. Please describe the Ryan White HIV services offered in your area.
2. What other non-Ryan White HIV services are offered?
3. How do you feel about the type and amount of Ryan White Services available in your area?  
Too much? Too little? Need other services?
4. Now, what services have you used within the past year?
5. What has been your greatest need in the past year?
6. Were you able to receive services to assist you with that need? Why or Why not?
7. What are some barriers you have in getting services in your area?
8. How do you feel about the type and amount of Ryan White Services available in your area?  
Too much? Too little? Need other services?

9. What do you feel has been your greatest strength in living with HIV?

Why?

How has this helped you in getting services?

10. What are some ideas on how to increase getting services you or others in your area need?

Is there anything else anyone would like to add?

Thank you very much for participating in this discussion group! Good night.

**Appendix D**

**Guidelines for Facilitating**

**Small Group Discussion Sessions**

# **STATEWIDE COORDINATED STATEMENT of NEED (SCSN)**

Charlottesville, Virginia, June 18, 2004

## **GUIDELINES FOR FACILITATING SMALL GROUP DISCUSSION SESSIONS**

### **PURPOSE OF THE SCSN:**

To provide a mechanism to collaboratively identify and address significant HIV care issues related to the needs of people living with HIV/AIDS (PLWH/A), and to maximize coordination, integration and effective linkages across the CARE Act Titles related to such issues.

### **MEETING OBJECTIVES:**

#### **The SCSN meeting will**

1. Provide an opportunity to discuss unmet needs of persons and families living with HIV/AIDS;
2. Identify barriers to and critical gaps in HIV care services;
3. Identify cross-cutting issues applicable across geographic areas, demographics and the entire spectrum of HIV/AIDS; and
4. Formulate broad goals for use in future planning that address barriers, gaps and cross-cutting issues.

### **PROCESS/MISSION:**

A breakout group will involve 12 to 14 individuals who represent a mix of interests, opinions and geographic areas. The facilitator will create an inclusive environment that encourages sharing different perceptions and points of view.

- A facilitator team will be used with divided tasks. The main facilitator will direct the discussion and take minimal notes. The reporter will take comprehensive notes, operate the tape recorder, and respond to unexpected interruptions (e.g., late comers). VDH staff will circulate between groups to assist the facilitator team as needed.
- Individuals will be assigned to groups to make sure there is an appropriate mix of participants in each session. Sign-up sheets will be provided to the facilitator team to document attendance.
- Approximately 3 hours 45 minutes is allocated to small group discussion. Breaks are scheduled at appropriate intervals.
- Discussions should be recorded via audio taping and note taking. Ask the group's permission to ensure that audio taping is acceptable to everyone. You will need to tape the group's verbal ascent for documentation purposes. If anyone in the group does not



agree, do not tape the session. Notes may be taken on a flipchart and/or paper. The report form should be completed by the reporter before leaving the event (see attached form).

- The facilitator will help the group accomplish predetermined tasks, move through the agenda in the time available, and guide the group toward accomplishing the SCSN Meeting Objectives. The facilitator will highlight how this small group discussion will build on, not replicate, the pre-meeting discussion groups held for PLWH/A on 6/17/04. While individuals' past experiences with services may be relevant to the discussion, this is not a forum to address grievances or dwell on complaints about a specific service provider. Individuals with this need can be referred to a VDH staff member who can direct the individual on how to have grievances addressed.
- The facilitator team will help collect evaluation forms from all members of the Small Group Discussion.
- Immediately after the session, facilitator and reporter will check the tape recorder to make sure it recorded. If it didn't, the team should do their best to reconstruct the discussion immediately. Otherwise, the reporter will complete the Small Discussion Group Report Form and turn it in to the registration table. The reporter will use the audio tape, notes and flipchart to prepare a complete summary of the discussion. This written summary should be prepared as soon as possible after the session and presented at the next SCSN steering committee meeting.

### **Small Group Discussion Sessions Guide for Facilitators:**

#### **SESSIONS 1 & 2**

**Introductions (Session 1 only)** - Introduce self as the facilitator and welcome participants. Pass around sign-in sheet and ask participants to complete the information. Participants should be encouraged to introduce themselves by name or pseudonym (if they prefer) and share with the group their answer to the following question:  
**“What made you want to participate in the SCSN meeting?”**

#### **Ground rules (Session 1 only)**

Participation by all is encouraged. Establishing ground rules usually helps a group to function effectively and meet its objectives. Elicit ground rules from the group that will make individuals comfortable participating. Record on flip chart and post. Ensure the following are included:

1. Only one person talks at a time. (Do not engage in side conversations.)
2. Raise your hand if you would like to make a comment.
3. Be respectful of one another.
4. Observe confidentiality of personal information or experiences that may be shared in the course of the discussion. Comments will not be attributed to a specific individual in any report outside of the group.

### **Overview of small group sessions (Session 1 only)**

Explain that Sessions 1 and 2 will focus on looking at the summary of the top 8 unmet needs identified by reviewing existing regional needs assessments. Barriers and gaps in service that prevent these needs from being met will be identified along with solutions and strategies to address them.

Emphasize that the small group discussion will build on (not repeat) the pre-meeting discussion groups held on 6/17/04. While an individual's past experiences with services may be important as an example or to help another participant to understand a need or barrier, today's discussion is not the time to complain about a specific service provider. (See 5<sup>th</sup> bullet above for individuals who need an avenue to address specific grievances). Ask the group to assist by following the facilitator's lead in re-directing the discussion if this situation comes up.

Session 3 will examine common threads, themes or cross-cutting issues that fall out of the discussions during sessions 1 and 2. This final session will focus on developing broad goals to guide planning for services in the future. Time will be provided to complete evaluations at the end of the session

Prepare participants by explaining that a variety of group techniques will be used during these sessions because individuals tend to have different preferences about how they like to participate. The facilitator and reporter will work together to keep the discussion focused and on schedule so that all the important parts of the SCSN are covered and everyone has a chance to say what they think. Ask participants to assist by being sensitive to the time limits and follow the facilitator's lead when it is time to move on.

### **Address needs**

During Session 1, the discussion will focus on the following health care related needs: Dental (ranked as greatest unmet need), Medication (ranked 2<sup>nd</sup>), and Primary Medical Care (ranked 7<sup>th</sup>).

During Session 2, the discussion will focus on the following support related needs: Transportation (ranked 3<sup>rd</sup>), Emergency financial assistance (ranked 4<sup>th</sup>), Help receiving government benefits (ranked 5<sup>th</sup>), and Case management (ranked 8<sup>th</sup>).

- Validate these needs by asking group:

**“How do these needs match your experience (personal experience or what you have observed as a provider)?”**

Use a round robin approach where all are encouraged to take a turn with the option to pass or opt out. Listen and validate all responses. Record any other related critical needs that are voiced.

### **Identify and prioritize barriers**

- Ask group: **“What barriers get in the way of getting these needs met?”**

Encourage participants to brainstorm for 5 minutes. Record all responses on flipchart. No comments from facilitator or group, only clarification as needed so it can be recorded.

- ✓ Use prompt questions as needed:
  - “What barriers create or contribute to the needs we have talked about?”**
  - “Name a common barrier to HIV care in your community.”**

When brainstorming time is up, go back over the list to refine it. Check in with the group as needed to collapse similar barriers or specify if a barrier is related to a particular need. Develop a consolidated list of barriers written clearly on flipchart sheets with 1-2” space between each barrier. Post the sheets where they will be accessible for voting (see below).

Prioritize barriers by using a simplified nominal ranking process. Each participant gets 3 “votes” represented by stickers (which will be provided). Each color represents how important a barrier is: red is most important, blue is second most important, and yellow is third most important. Each participant will designate which barriers are the most significant by placing their stickers next to it. Invite the group to stand up and in an orderly fashion, place their stickers next to the barriers they would like to vote for.

Reporter should tally the ranking by using a point value for each color: red=3 points, blue= 2 points and yellow= 1point. Re-write barriers in the order that they received votes (highest points=most important) and post. Spend just a few moments processing the ranking by looking at least at the top three barriers.

- Ask: **“Why do you think this barrier got ranked 1<sup>st</sup>, 2nd or 3rd?”** Ask about as many barriers as time allows.

- ✓ Use prompt questions as needed:
  - “What makes this barrier so important?”**
  - “Who is impacted by this barrier?”** May probe whether this barrier is specific to a particular region or jurisdiction; group or population (women, minorities, injection drug user’s etc).
  - “Why do you think this barrier got this amount of votes?”**

### **Identify gaps in service and strategies to fill gaps**

Use a variety of open-ended questions to clarify where there are gaps in service that create or reinforce barriers and to identify potential solutions.

- Ask about gaps: **“What services are missing?”** List gaps.
  - ✓ Use prompt questions as needed:
    - “What gaps in service do these barriers point to?”**
    - “What population(s) is/are missing out?”**
- Also ask about solutions, **“What would make it easier for you or your clients to get what you (or they) need?”** List services/solutions.
  - ✓ Use prompt questions as needed:
    - “What services/solutions could be changed or put in place to overcome the top 3 barriers (cover additional barriers as time allows)?”**

- ✓ Use a couple of the following “Nth degree” questions to identify key strategies. Mark strategies identified as key with an asterisk.  
**“If you could add just one service, what would it be?”**  
**“What service or other solution could be put in place to take care of more than one barrier?”**  
**“What solution do you think gives the ‘most bang for the buck’?”**  
**“What is the most important service that is not available but should be?”**

If group is having trouble coming up with services/solutions/strategies, stop the discussion and invite participants to take a few minutes to think quietly on their own. Each individual should jot down insights or ideas. Reconvene and ask individuals to share what they have written. Write responses on the flipchart.

### **SESSION 3-** 3:15-4:00

#### **Identify cross-cutting issues**

Ask participants to reflect back on their SCSN experience so far. Refer back to the opening sessions of the day and the small group discussion that followed. Invite participants to consider all they have seen, heard and shared during the SCSN Meeting.

- Ask the group:  
**“What repeating issues or recurring themes have come up?”** List and consolidate like responses.
  - ✓ Use prompt questions as needed:  
**“What common threads connect the 8 needs we discussed in session 1 & 2?”**  
**“What similarities/ differences do you see between what we have talked about so far (needs/barriers/gaps/solutions)?”**  
 Ask group input and clarification to phrase 2-3 cross-cutting issues. Cross-cutting issues could include trends, problems, or concerns. Examples would include things like “More collaboration is needed among service providers”, “How will the changes to Medicare impact services?” or “Why don’t more teens access HIV-related services?” etc.
- ✓ If the group is having trouble identifying cross-cutting issues, you may need to probe further with  
**“What did you hear over and over during today’s discussion?”**  
**“What insight did you gain or “Ah Ha” moment came to you today?”**  
**“What surprised you in today’s discussion?”**

#### **Establish broad goals**

Emphasize the importance of this last step in the process. An important part of the SCSN is providing guidance for the future. Setting a broad goal can provide this guidance. Goals can be creative Think big! Encourage participants to think about what they would like to see happen to HIV services. Phrase this vision in the form of a goal. Ideally, goals would address cross-cutting issues. Examples of goals could include “All consortia

will recruit participants from all RW CARE Act Titles in their region.”, “Written policy will be developed to address new Medicare benefits impact on eligibility for services” or “A teen-friendly network of service providers will be established to accept referrals from test sites and school health programs.” Each group should establish at least one broad goal.

- ✓ If formulating a goal proves difficult, prompt discussion with the following questions:
  - “What do you see as the highest priority goal for improving HIV-related services?”**
  - “What is the most important thing Virginia could do to improve health and quality of life for people with HIV?”**
  - “What steps can be taken to move the level of care forward?”**

### **Conclusion and Evaluations-4:00-4:15**

Thank group members for their contributions and participation. Remind everyone to complete their evaluation forms. Ask for any suggestions to improve the SCSN process for the future and encourage participants to include this in their evaluations. While forms are being completed, thank participants for all that they have given to the SCSN process. Provide some closure to the day by asking participants to think about what they want to take away from the SCSN process. It could be a new idea, an insight, a question, an issue to tackle, a new support person, etc. Ask for volunteers who would like to share what they will be taking away. Do this briefly, validating all responses. Collect evaluations and provide “Thank you” bags that contain incentives. Adjourn session.

### **Small Group Discussion Summary**

By the end of the sessions groups will have

- Reviewed the summarized needs assessment
- Discussed unmet needs
- Identified and prioritized barriers to care
- Identified gaps in HIV care services
- Proposed services, solutions and strategies to overcome barriers and fill gaps
- Identified cross-cutting issues, and
- Formulated at least one broad goal to improve services for PLWH/A

### **WRAP UP**

It is vitally important for the facilitator and reporter to take a few minutes to wrap up the session by following these steps:

1. If audio taping was used, check that the tape recorded the discussion. Label tape with facilitator’s name.
2. If tape did not work or group declined taping, take a few minutes to review notes and flipcharts. Discuss and record key points and observations that were not captured.
3. The reporter will complete the Small Discussion Group Report Form and turn it in with the evaluations forms to the registration table.
4. The reporter should take the audio tape, notes and flipchart papers to use to prepare a complete summary of the discussion. This written summary should be prepared as soon

as possible after the session and presented at the next SCSN Steering Committee Meeting.

5. All other materials can be left in the room. VDH staff will come by and collect them.

## **Appendix E**

### **SCSN Evaluation Report**

## **STATEWIDE COORDINATED STATEMENT of NEED**

JUNE 17-18, 2004

CHARLOTTESVILLE VIRGINIA

### **EVALUATION RESULTS**

The Virginia Statewide Coordinated Statement of Need (SCSN) was held June 17 and 18, 2004, in Charlottesville, Virginia.

To evaluate the quality of the meeting itself, an evaluation instrument was designed and administered to all participants at the conclusion of the meeting. The meeting evaluations had some general questions and some questions oriented to the specific agenda items. In addition, open comments were part of each meeting evaluation to allow attendees to provide any thoughts they felt appropriate.

There were 107 people who attended the meetings.

#### **Evaluations of the June 17<sup>th</sup> Pre-Discussion Group:**

There were 77 attendees and we received 66 responses to the evaluations. The first six closed-ended questions were rated using a scale with the following four response options: strongly agree, agree, disagree, and strongly disagree. A majority of those who filled out evaluations (70% strongly agreed and 29% agreed) felt that they were able to express their feelings and needs. Ninety-nine percent strongly agreed or agreed that the meeting was well organized and 100% strongly agreed or agreed that the facilitators were receptive to their comments. More than 95% of the respondents felt the Pre-Meeting Discussion Group was useful, the content of the meeting was consistent with their expectations, and that by the end of the session, they were ready to participate in the SCSN meeting. Overall, the evaluation of the June 17<sup>th</sup>, 2004 Pre-Discussion Group was overwhelmingly positive.

#### **Evaluations of the June 18<sup>th</sup> SCSN Meeting:**

Out of the 107 attendees, 100 evaluations were received. Among the respondents, 71 individuals self identified as living with HIV/AIDS. Twenty-four of the respondents were from Central, 19 from Eastern, 21 from Northern, 18 from Northwest, and 16 from Southwest.

The first seven questions were rated using a scale with the following four response options: strongly agree, agree, disagree, or strongly disagree.

**SCSN Morning Session:** Ninety-eight percent of respondents strongly agreed or agreed that the SCSN objectives and process were clearly explained and the report from the Pre-Meeting Discussion Groups was clear. Ninety percent of those who filled out evaluations indicated that the epidemiology data was presented in a way that they could understand.

**SCSN Breakout Sessions:** Ninety-two percent of the respondents agreed that the breakout sessions were well organized, the facilitators were well prepared, and that participants were able to share their point of view. There was a mixed response to the question related to the time allotted to each session. Seventy-seven percent of the



respondents felt that enough time was allotted to each session, while 20% of respondents disagreed.

### **Overall Meeting Evaluation:**

To the question, “Was the publicity effective in recruiting representative participation?” 85% of the respondents responded “Yes” and 7% answered “No”. Eighty-eight percent felt that the SCSN objectives were achieved and the same percent of the respondents said that they were satisfied with being able to participate and fully express their opinion.

Respondents were asked to rate aspects of the event using a 4 point scale where 4 = excellent, 3 = good, 2 = fair, and 1 = poor. Average score was calculated by multiplying the point value by the number of respondents who assigned that rating to that item then dividing by the number of respondents to that item. Response rates varied substantially among these items.

	Excellent	Good	Fair	Poor	Total Points	Average
<b>Location</b>	148	87	18	1	254 (76)	<b>3.34</b>
<b>Hotel</b>	132	99	12	0	243 (72)	<b>3.38</b>
<b>Food</b>	64	105	30	9	208 (75)	<b>2.77</b>
<b>Morning Presentations</b>	168	108	20	1	297 (89)	<b>3.34</b>
<b>Small Group Discussion Session</b>	240	75	6	2	323 (90)	<b>3.59</b>
<b>Overall Meeting</b>	188	114	4	0	306 (87)	<b>3.52</b>

- () - Number of respondents.

Small Group Discussion Session had the highest rating, 3.59 out of 4.

Most respondents also felt that the overall meeting was close to excellent with 3.52 points out of 4.

Ratings were somewhat lower with regard to the food, 2.77 out of 4.

Location, hotel, and morning presentations exceeded the good rating, according to the respondents.

### **Comments:**

Participant comments are summarized below. We have grouped common comments by the following categories: SCSN morning session, SCSN breakout sessions, overall meeting, and suggestions.

As shown below, the majority of those who completed the evaluations felt that the meeting was well organized and productive. Comments include concerns about attendance, suggestions for the improving the SCSN, feedback on various activities, and positive reflections on the SCSN meetings.

Some common themes are captured by the following representative comments:

**Pre-Meeting Discussion Group:**

This meeting helped prepare me for the SCSN meeting, gave me a better insight on subject matters.

I enjoyed it. I was able to express and hear those from other regions.

It helped to understand how the needs assessment has been handled.

The meeting was great.

I felt this meeting was much too unstructured and several individuals used up valuable time in discussing personal data, which was often unrelated to the subject matter at hand.

**SCSN Morning Session:**

Morning session was very interesting because a lot wonderful input was given.

The epidemiology presentation was a bit too drawn out, lost interest and too many terms not identified. Geocoding was interesting but not relevant.

The report from Pre-Meeting Discussion was very good.

**SCSN Breakout Sessions:**

Wonderful opportunity for all involved to voice feelings/opinions on the topics –

Great work.

Facilitator was very good in direction and stimulating discussion.

Facilitator was not very knowledgeable about HIV/AIDS services.

Facilitators followed their own rules.

Some participants dominated conversations.

Group too large and having two groups in the same room was uncomfortable.

Very useful to communicate with others and learn from their experiences and ideas.

**Overall Meeting Evaluation:**

This was one of the best SCSN meetings I have been to.

Food was poor.

I learned from persons coming from other areas.

Hotel was not really for this size group.

It was good to share my unmet needs.

VDH staff was understanding and respectful.

Need another SCSN in the future.

Overall it was an excellent meeting with meaningful information.

The facilitators were great.

**Suggestions:**

- Suggestions for future breakout groups included limiting the groups to 8-10 people.
- Other suggestions included avoiding having participant lists in front of each meeting room.
- The majority felt the pace of the meeting was uncomfortable.
- A majority of participants want to receive the final report of the SCSN.

- There were several suggestions about the format of the meeting including increasing its length and starting earlier.
- Need to allot more time for breakout sessions for discussion.
- For future meetings, attention was paid to providing bottle water and healthier snacks.
- More information or better training is needed for case managers due to lack of experiences in dealing with HIV individuals.
- Epidemiology data needed to be simpler.
- To make experience better, best to get facilitators together for 2-3 hours before the meeting.
- Need a larger hotel for the future.
- Need presentation by a case manager and a medical provider – What they do and guidelines for practice.
- Would like a feedback session after breakouts.

### **Conclusion**

The evaluations have provided a wealth of positive feedback as well as some important constructive criticism. This information, along with the many comments we received, will assist us in planning future meetings. The Division of HIV, STD, and Pharmacy Services wishes to sincerely thank the meeting participants and especially the Steering Committee members and facilitators for their input and their efforts to improve the SCSN.